

# CHILDREN'S CONSENT FOR HIV SERVICES

A Policy Analysis of the Health, Social Welfare, and Education Sectors in Kenya



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## Abbreviations

ART	antiretroviral therapy
CHALN	Canadian HIV/AIDS Legal Network
COE	Council of Europe
HP+	Health Policy Plus
IASSW	International Association of Schools of Social Work
IFSW	International Federation of Social Workers
MGCSD	Ministry of Gender, Children and Social Development
MLSS&S	Ministry of Labour Social Security and Services
MOE	Ministry of Education
MOH	Ministry of Health
MOPH	Ministry of Public Health and Sanitation
NACP	National AIDS Control Programme
NASCOP	National AIDS & STI Control Programme
NCCS	<b>National Council for Children's Services</b>
OAU	Organisation of African Unity
OHCHR	Office of the United Nations High Commissioner for Human Rights
RELAF	Red Latinoamericana de Acogimiento Familiar
ROK	Republic of Kenya
UN	United Nations
UNGA	United Nations General Assembly
UNICEF	<b>United Nations Children's Fund</b>
USAID	U.S. Agency for International Development
WHO	World Health Organization

## Executive Summary

Through incorporation of international law, participation in international treaties, and new policy documents such as the 2010 Constitution, Kenya has a strong underlying policy **foundation establishing the rights of children and is evolving in its practices related to children's** rights. However, there is not a national, comprehensive guiding policy standard for how to manage the engagement of children in the decisions effecting their health and health data (e.g., in the Health Act or Children Act) against which sector- and service-specific policies and guidelines must align on the components of consent, the authorization for consent, or the contexts in which consent applies.

**Kenya's** health, social welfare, and education sectors have best practices that may be adapted and applied across sectors. In general, this assessment found that across the three sectors, general medical policy is stronger on issues of formal informed consent, HIV providers are more comfortable with lower ages of consent, and both general and HIV-specific social welfare practices are strongest on integrating child assent and assessing and developing caregiver **capacity to support children's consent processes** throughout program implementation.

**The policy and guideline framework related to consent for children's access to HIV social and** medical services and management of confidential HIV data is a patchwork of conflicting, inadequate, and often absent policy. This fragmented policy environment contributes to the programmatic experience described by providers, policymakers, and adolescent representatives in which consent practices for children are ad hoc and inconsistent. This policy and ad hoc practice environment contributes to risk for providers in an increasingly litigious culture, as well as children for whom consent may not be sought or obtained.

Findings of the policy assessment (summarized in Annex A) can be divided into two groups. In the first group is the enforcement and enactment of existing rights to health, protection from harmful cultural practices, ensuring the best interest of the child, and maturity-aligned participation. The second group consists of the need for service-specific policy guidance that is consistent across health, social welfare, and education sectors for clear and consistent assent and consent guidelines related to medical and social HIV services and sharing of confidential HIV data.

While there are certainly strengths in the policy framework and in sector practices, there are also critical weaknesses that affect access to and retention in HIV services for children, especially most-at-risk children. Most critical are the need to align consent policy for HIV testing and treatment and the need for enforcement and redress mechanisms for breaches of consent—particularly in the education sector.

# Introduction

## Purpose

Childhood and adolescence is a period of rapid social, cognitive, and physical development, and **engagement of this population must align with the individual's capacity to make decisions.** During this period of physical and psychological development, children are generally extraordinarily self-conscious, and many of their health-related problems are associated with behaviors that they find shameful and embarrassing—which can be exasperated for children at risk for or living with HIV.

Clinical and social service providers recognize that, in many settings, children—especially those who are vulnerable and marginalized—are at high risk for HIV, with limited access to prevention and diagnostic services and poor treatment outcomes. However, many HIV prevention, testing, treatment, and care policies and guidelines for informed consent and the management of confidential HIV data are not designed to address the needs and contexts of children. For example:

- The lack of training, tools, and staffing required to navigate the cultural, social, and moral complexities of children prevents most providers from addressing the compounded needs of HIV during a particularly challenging time in life.
- Provider decision making regarding consent can be influenced by personal opinions and a lack of clarity in laws and guidelines.
- Inconsistent policies and practices in assessing child capacity to give/withhold consent and the related need for caregivers to help children navigate consent decisions puts providers at legal and professional risk **and creates barriers for children's access to HIV-related services and effective management of confidential HIV data** (WHO, 2013b, pg. 18).

In January 2018, the Health Policy Plus (HP+) project, funded by the U.S. Agency for International Development, **conducted a consultation on children's consent in Kenya. The purpose of this consultation was to gain insight into the country context of children's consent for HIV services and to validate the need for and concepts of the Children's Consent Framework,** currently in development. HP+ staff met with government and donor stakeholders, organizations implementing medical and social welfare HIV services for children, and youth representatives. Consistent themes from these meetings included:

1. Both overarching and HIV-specific **children's consent policies were** at best conflicting, often inadequate, or absent.
2. Most HIV programs were child-centered and engaged children in decision making, but consent practices were ad hoc.
3. The core principle of maturity-aligned consent resonated with stakeholders.

The purpose of this assessment is to combine this stakeholder feedback with documentation of the language of policies and guidelines in Kenya to identify policies that are enabling, absent, **conflicting, restrictive, or inadequate in guiding the practices related to children's consent for HIV-related medical and social services and management of confidential HIV data.**

This assessment is grounded in the perspective that policies must be responsive to the most vulnerable and marginalized children who are at the highest risk for HIV and poor treatment outcomes—children excluded from services because of age, lack of information, discriminatory attitudes of service providers, gender-based discrimination, and societal norms (UNICEF, 2015, pg. 12). This vulnerability stems from little or no access to basic needs and rights, including a **“right to a safe home and community environment; education; love, family care and support; sufficient food and nutrition; protection from maltreatment and neglect; protection from abuse and violence; adequate clothing; and the right to make lifestyle choices”** (WHO, 2011, pg. 26).

## Definitions and Terminology

The following terms are used as defined below throughout the document.

**Children:** Anyone under the age of 18, regardless of legal, cognitive, and social capacity to consent.

**Caregiver:** An individual who (1) has the cognitive and social capacity to make decisions regarding HIV-related social and medical services and management of confidential HIV data, and (2) is supportive of the child. This individual may be a parent, guardian, another child or peer, healthcare/social service provider, informal caregiver, or other supportive individual.

Policies in the health sector tended to use the terms “parents” and “guardians,” while policies in the social welfare sector use the terms “parents” and “caregivers.” Stakeholder consensus was to use the term “caregiver,” as it is more encompassing than the narrow legal definition of guardian and reflects the reality of most-at-risk children, especially those whose parents are not present or supportive.

**Confidential HIV data:** Information that indicates HIV-positive or -negative status or risk (e.g., results of tests, participation in medical or social support interventions, or behavioral risks).

**Sharing confidential HIV data:** Confidential HIV data shared (or consented to be shared) by an individual who owns these data, either because the data is related to themselves and/or related to a person for whom the individual has consented (e.g., mother sharing the HIV status of an infant).

## Alignment across Health, Social Welfare, and Education Sectors

Children and their caregivers interact with providers across multiple sectors and their experience in one sector informs a collective perspective of how the rights of children will be

### Disclosing a Child's HIV Status to the Child

Consent to share confidential HIV data in this document is not specific to child disclosure protocols. However, there are some common relevant issues.

The confidential HIV data of a child for whom a caregiver has been providing consent “belong” to that caregiver and, as such, the caregiver must give consent for them to be shared with the child.

Disclosure to a child of their HIV status may, by proxy, disclose the status of parent(s). The HIV status of the parent(s) is their personal HIV data and, as such, requires the consent of the parent to disclose to the child.

Strong policy language on the paramouncy of the best interests of the child and the authority of a provider to make consent decisions in the absence of a supportive caregiver can guide difficult decisions if parents are resistant to providing consent to inform a child of the child's HIV status.



approached by service providers in general. For example, stakeholders described experiences of children's **HIV status being** broadcast without consent in school settings. This experience of witnessing the careless and non-consensual sharing of children's status (and by proxy, potentially the status of the parents), and the perceived or real risk that it will happen again becomes part of the risk-benefit analysis that children and their caregivers make when they are considering accessing HIV-related medical or social services.

Another reason for looking across sectors is to identify best practices that may be adapted and applied in other settings. This assessment found that among the health, social welfare, and education sectors, general medical policy is stronger on issues of formal informed consent, HIV providers are more comfortable than social welfare providers with lower ages of consent, and both general and HIV-specific social welfare practices are stronger on integrating child assent and assessing and **developing caregiver capacity to support children's consent processes** throughout program implementation.

This assessment focuses on HIV-related services and information because of the critical issues involving real, perceived, or feared stigma and discrimination, the potential for ongoing risk of transmission and need for identification of partners, and the experience of living with a chronic disease throughout the developmental stages of a childhood and adolescence. But overarching concepts regarding informed consent and confidentiality have broad application and can be broadly harmonized across many health and social services for children.

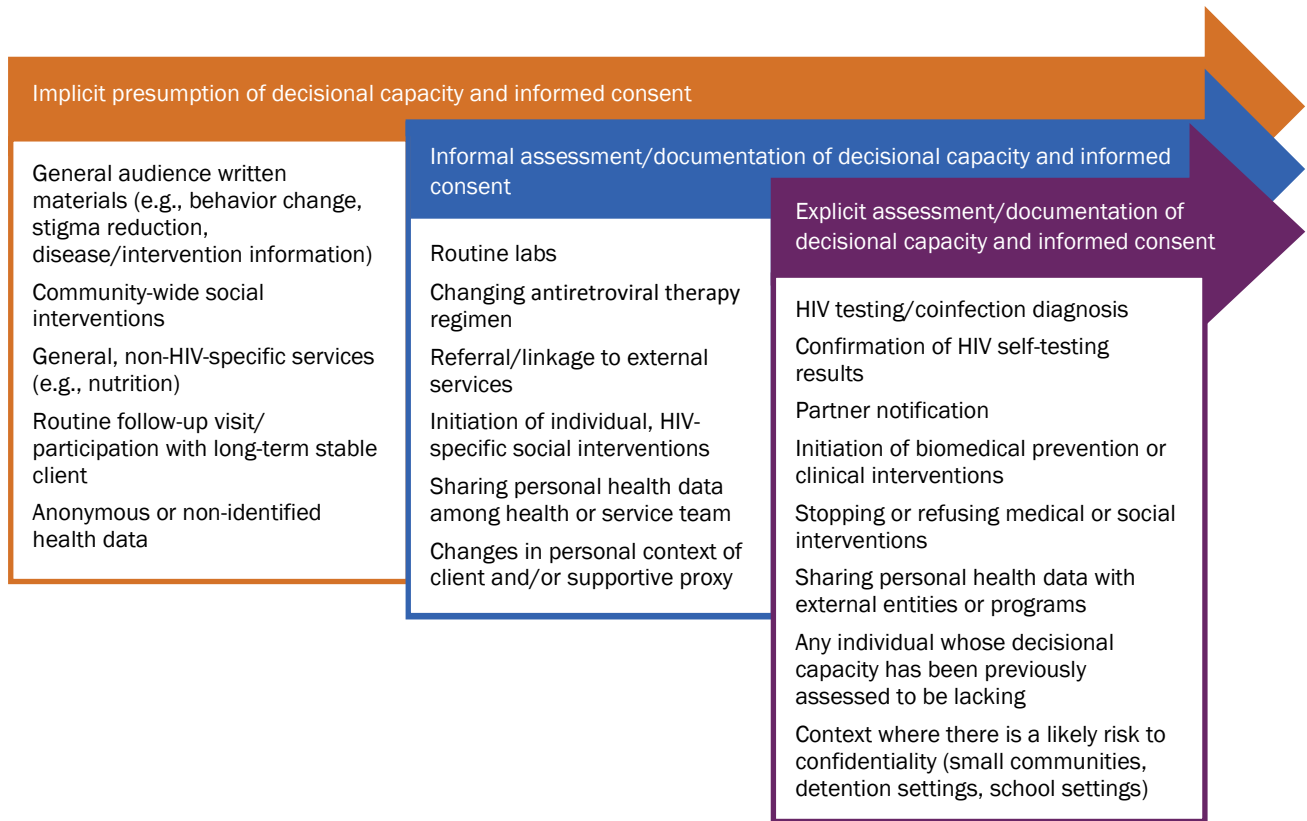
This assessment does not address consent and confidential data sharing issues for:

1. Suspected or documented emotional, physical, or sexual abuse
2. Underage sexual activity
3. Unconsented or coerced use of HIV self-testing technologies
4. Child abuse and neglect due to withholding of medical or social services
5. Required reporting of infectious diseases
6. Research
7. Exposure risk and treatment for providers in occupational settings
8. Emergency diagnosis and medical care or social support

It is also important to note that assessment of decisional capacity in the context of HIV medical or social services, or decisions regarding sharing of confidential HIV data, does not imply physical, cognitive, or emotional capacity to consent for all medical and social services or capacity on issues such as marriage, sexual behavior, or criminal/legal liability.

## **Incremental Implementation**

Finally, while core values of informed consent/refusal and data confidentiality are non-negotiable, the decisions about the formality with which they are implemented should be scaled to the risk posed to the provider or child by the HIV medical or social intervention or HIV data sharing request. As risk grows, the implementation of consent requirements moves from implicit to explicit and documentation may move from assumed to verbal to written. To reduce implementation inconsistencies, program managers need to consistently map the intervention on a risk spectrum and align the application of consent practices accordingly.



## Policy Assessment

### Rights

The Kenya Constitution incorporates both international law and any ratified convention or treaty into the laws of Kenya (ROK, 2010, Art 2[5][6]). Among many other related instruments, Kenya ratified the Convention on the Rights of the Child in 1990 and the African Charter on the Rights and Welfare of the Child in 2000.

**The Kenya Constitution specifically identifies a fundamental duty of the State to “observe, respect, protect, promote, and fulfill” the rights of children and youth** (ROK, 2010, Art 21[1], [3]). The Children Act **commits the government to “achieving progressively the full realization of the rights of the child” to the “maximum of its available resources”** (ROK, 2001, Art 3), the HIV and AIDS Prevention and Control Act extends full protection of human rights and civil liberties for every person suspected or known to be infected with HIV (ROK, 2006, Art 3[b]), and the vision of the **National Children Policy is to “create an environment where all the rights of the child in Kenya will be fulfilled”** through objectives that include a holistic, coordinated, and evaluated policy framework (NCCS, 2010, pg. 7).

In the education sector, child rights, protection, and responsibilities are a component of school health programming, with a focus specifically on the rights to play, leisure, and participation (ROK, 2009a, pg. 10, 19, 22).

Following, we explore the **key rights most relevant to the policy environment for children’s consent—the right to health, protection from harmful practices, acting in the best interest of the child, and the child’s right to participation.**

### Right to Health

Both the Convention on the Rights of the Child and the African Charter on the Rights and Welfare of the Child identify health as a **child’s** right (OAU, 1990, Art 14[1]); UNGA, 1990, Art 24[1]). The Kenya Constitution and Health Act also provide for this right and include the right to healthcare services, including reproductive healthcare for all men and women of reproductive age (ROK, 2010, Art 43[1][a]; ROK, 2010, Art 53[1][c]; ROK, 2016, Art 3[a][b]; ROK, 2016, Art 6[1][a]). Antiretroviral therapy (ART) guidelines direct that all people living with HIV qualify for ART (MOH, 2016, pg. 19).

However, ART guidelines identify an uncited contraindication for pre-exposure prophylaxis in adolescents under 15 years of age. Thus, while there is no specific guideline on age of eligibility or process for consent in either the pre-exposure prophylaxis guidelines or implementation framework, **this “contraindication” creates an informal** restriction on this health service (MOH, 2016, pg. 132; NASCOP and MOH, 2017).

#### Finding

1. While the right to reproductive healthcare is well established, access to and consent for pre-exposure prophylaxis for HIV is not clearly defined and is indirectly restricted for those under the age of 15—with or without parental/caregiver consent.

## Protection from Harmful Cultural Practices

Article 21 of the African Charter on the Rights and Welfare of the Child requires Kenya to eliminate harmful social and cultural practices and customs, particularly those prejudicial to the **child's health or life and those that are discriminatory** based on sex or other status. The Constitution also calls for protection from harmful cultural practices (OAU, 1990, Art 21[1]; ROK, 2010, Art 53[1][d]).

Kenya's policies identify cultural and traditional practices as one of the major challenges to the full realization of child rights in Kenya. **Harmful cultural practices are defined as "activities that impact negatively on a child's physical, emotional and behavioral development, their general health, his/her family and social relationships, self-esteem, educational achievements and aspirations"** (MGCSD, 2013, pg. 64). Protections from **"retrogressive and repugnant cultural, beliefs and practices"** (NCCS, 2010, pg. 15) apply to institutional, education, and health settings (MOPH and MOE, 2009, pg. 17; NCCS, 2010, pg. 9; MGCSD, 2013, pg. 64).

In spite of these protections, negative cultural and religious beliefs of providers are still cited as **"the single most important barrier to youth access to reproductive health services"** (MOH, 2005, pg. 11, 16).

### Finding

2. Children are broadly protected from activities and beliefs that negatively impact their health; however, the religious and cultural beliefs of providers are still significant barriers to youth's access to reproductive health services.

## Best Interests of the Child

The Convention on the Rights of the Child identifies that, for all actions concerning a child, the best interests of the child shall be a primary consideration, while the African Charter on the Rights and Welfare of the Child requires that the best interests of the child be *the* primary consideration (OAU, 1990, Art 4[1]; UNGA, 1990, Art 3[1]). This is an important distinction, as the use of the indefinite article **"a"** only requires that the best interests of the child be considered as one among many other considerations. The use of the definite article **"the"** prescribes a higher standard—that where there are any competing interests (e.g., cultural, economic), the well-being and safety of the child is of overriding importance (Lloyd, 2002). For example, the Convention on Human Rights and Biomedicine indicates that the interests and welfare of the individual shall prevail over the interests of society and science (COE, 1997, Art 2).

The shift from the best interests of a child being **"a"** primary consideration to **"the"** primary consideration reflects a cultural shift from children being the property of their parents to children being full rights-holders with a degree of self-determination (Lloyd, 2002).

This evolution requires both policy reform and a fundamental philosophical shift on the part of providers and caregivers to assure the effective engagement of children in the decisions regarding their care.

The Kenya Constitution aligns with the higher standard and stipulates that **a child's best interests** are of paramount importance in every matter concerning the child (ROK, 2010, Art 53[2]). This higher standard is reflected in the National Children Policy (NCCS, 2010, pg. 7, 8) and for victims of violence against children (ROK, 2014c, Art 17[5][c]).

However, policy language in the Children Act (perhaps because it was written before the new Constitution) stipulates that the best interests of the child:<sup>1</sup>

- Are only a primary consideration (ROK, 2001, Art 4[3])
- Should be taken into account (ROK, 2001, Art 69[3])
- Should be given regard to (ROK, 2001, Art 83[1][j], Art 148[5], Art 187)
- Must be reasonable (ROK, 2001, Art 100)

Guidelines for alternative care of children clearly identify the best interest of the child as a core value and integrate the need for best interest assessment and determination. But the guidelines are inconsistent, both aligning with the Children Act and the Convention on the Rights of the Child as well as referring to best interests as paramount in guiding the selection of foster parents and guaranteed during a guardianship process (ROK, 2014a, pg. 62, 78). Psychosocial support guidelines place the best interests of the child in the vaguely expressed “**center of all decisions,**” while not specifying where it ranks relative to other central considerations (MLSS&S, 2015, pg. 2).

Also failing to meet the constitutional standard are HIV policies in the education sector which stipulate that the best interests of the child **only** “guide” decisions related to sharing confidential HIV data (ROK, 2013, pg. 6–7). And key HIV policies from the health sector are either silent on the concept of best interest of the child or fail to elevate this right above all others (MOH, 2005, 2012, 2013, 2014, 2016; NACP, 2002).

## Findings

3. The Children Act does not reflect the standard of ensuring that the best interests of the child are paramount, as reflected in the Constitution (may be resolved in the new 2018 Children Act).
4. The Guidelines for Alternative Care are inconsistent in their prioritization of the best interests of the child.
5. Guidelines for the education sector do not reflect the standard of ensuring that the best interests of the child are paramount, as reflected in the Constitution.
6. HIV policies are entirely silent on the paramountcy of the best interests of the child.

## Children's Right to Participation

The Convention on the Rights of the Child identifies that children must provide their views and have their view given due weight on issues that will affect them (OHCHR, 2003, Art 28). Children who do not have the maturity to fully provide or withhold informed consent have the right to a maturity-aligned role in the decisions that affect them. In all cases, it is important to involve the child in decisions regarding their physical and social health and decisions on the management of confidential HIV data, commensurate to their developmental age and level of

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<sup>1</sup> As of the date of this assessment, a new Children Act 2018 was being drafted to replace the 2001 version reviewed for this assessment. While the final language was not available for assessment, draft language in the new 2018 Act appears to potentially address some of the findings in this report related to the supremacy of the best interests of the child.

maturity (WHO and UNICEF, 2010, pg. 2, 7). In the field of social work, this incremental engagement can be aligned to the concept of respecting the right to self-determination (IASSW and IFSW, 2012).

### **Maturity-aligned**

Current authorizing factors for providing consent in Kenya focus on biological (e.g., age, pregnancy) social (e.g., marriage, non-reliance on parents), or behavioral markers. However, current authorizing factors do not provide information on the capacity of the individual to engage in decisions related to HIV-services and data. Informed consent/refusal requires decisional capacity. At the very core of seeking informed consent is the assumption that the individual making decisions about the engagement/non-engagement in HIV medical or social services or the sharing/lack of sharing of confidential HIV data has the emotional and cognitive maturity to consent. This implicit, intrinsic, and requisite assessment of maturity should be present in every provider-child interaction, regardless of age of consent laws (Ho et al., 2005; Appelbaum, 2007; Chenneville et al., 2010; WHO, 2016a, pg. 116).

Kenya policies consistently require alignment of participation to the maturity of the child. The Children Act specifies **the requirement to take children's** opinions into account commensurate **to the child's** maturity (ROK, 2001, Art 4[4]). **The National Children's** Policy notes that the participation rights of children counter the sociocultural norm of ignoring children when making decisions that affect them and that this right requires the provision of accurate information to children at all stages of maturity (NCCS, 2010, pg. 16). Other policies require maturity-aligned engagement around the following topics:

- Participation and expression of opinion in matters affecting health and education in school settings (ROK, 2009c, pg. 25; ROK, 2009b, pg. 21)
- Involvement in development of individual childcare plans and making care decisions in institutional settings (MGCSO, 2013, pg. 52, 75)
- Best practices for the care of children (NCCS, 2011, pg. 150)
- Guidelines for engaging children in tracing and reintegration processes and decisions regarding adoption (ROK, 2014a, pg. 35, 84)

However, a maturity qualification authorizing an individual to provide or withhold consent for health services is absent in guiding policy language in the Health Act, **which only requires "legal capacity" to provide informed consent** (ROK, 2016, Art 9[3]). Maturity qualification is also absent in all HIV-testing guidelines, which favor biological, social, and behavioral markers to

"Young people know better how to identify their health and related needs. They are in a better position to prescribe solutions in meeting those needs. Their involvement in designing, planning, and running the services can greatly assist in mobilizing support and sustaining motivation to utilise the services by their peers." (MOH, 2005, pg. 18)

### **Example of Maturity-Aligned Language**

Consent for HIV services may be given by:

- ....
- ....
- the child, if the child is of sufficient maturity to understand the benefits, risks, and social implications of such services

(adapted from Government of South Africa, 2005, Sect 130)

indicate capacity to consent. Finally, none of the existing policy language supporting maturity-aligned engagement describes how to assess maturity.

### Findings

7. Existing indicators of capacity to consent are biological, social, and behavioral markers, rather than cognitive and emotional maturity measurements.
8. A maturity qualification to authorize an individual to provide consent is absent in overarching and HIV-specific health policy language.
9. Guidance on how to assess maturity is absent in existing language supporting maturity-aligned engagement.

### ***Assent/Dissent Required***

Assent/dissent is the requirement, for children without the capacity to provide informed consent, of engaging a child so that they understand, appreciate, and can give an opinion on accepting/rejecting decisions that are being made for them. This assent requirement applies to proposed interventions such as tests, therapies, and sharing of confidential HIV **data**. A **child's** dissent should be taken seriously, especially when the proposed intervention is not immediately essential and/or can be delayed without substantial risk (Bartholome, 1995).

Kenya's guidelines for caring for children and adolescents living with HIV specify that children be given the opportunity to contribute to plans for their care and sh always be allowed to express their opinion (MOH, 2015, pg. 52, 83, 84). Individual and institutional caregivers of children in social welfare and education sectors are directed to allow children to express their views and to take these views into consideration. (ROK, 2009c, pg. 25; ROK, 2009b; NCCS, 2011, pg. 147; MGCSD, 2013, pg. 52, 75). Furthermore, providers are directed to assess the awareness of a caregiver's **capacity** to support this participatory right of a child (MOH, 2015, pg. 66). However, none of these guidelines provide specific guidance on the components of assent or the process for managing dissent. Guidelines in the health sector are largely silent on the requirement for child assent.

### Findings

10. Policy language on child assent is largely absent in the health sector.
11. There is no specific policy guidance on the requirements and components of assent or the process for managing dissent.

### ***Informed Consent***

Informed consent, in varying degrees of formality, is required for medical and social services and may be withdrawn at any time. The Convention on Human Rights and Biomedicine states that health interventions may only be carried out after an individual has given free and informed consent (COE, 1997, Art 5). In addition, lessons learned from behavioral and social interventions with marginalized populations highlight the need for engaging participants in decisions as to whether they want to participate in social interventions (CHALN, 2007, pg. 11).



Consent is required for all interventions, including:

- Behavioral interventions (CHALN, 2007)
- Biomedical prevention (UNICEF, 2015, pg. 9–10; PEPFAR, 2017)
- HIV testing, including provider-initiated HIV testing and counseling (WHO and UNICEF, 2010, pg. 7; WHO, 2013b, pg. 46; WHO, 2016, pg. 51)
- Partner notification (WHO, 2016b, pg. 42)
- Medical treatment and ART (OHCHR, 2003, Art 29; WHO, 2013a, pg. 45)
- Care and social support (IASSW and IFSW, 2012)
- Sharing of confidential health data (WHO and UNICEF, 2010, pg. 10; WHO, 2013b, pg. 46)

In all settings:

- Hospital and clinical settings (WHO and UNICEF, 2010, pg. 7)
- Social work settings (IASSW and IFSW, 2012)
- School health settings (WHO, 2014, pg. 5)

The general components of informed consent are information on purpose, nature, consequences, and risk of the intervention, and understanding that patients may freely withdraw consent at any time (COE, 1997, Art 5). While there is no standard defining the components of informed consent in Kenya, there is a general policy consensus on these components. The Health Act identifies the components of consent as being information on health status, treatment options, benefits and risks, and the right to refuse treatment (ROK, 2016, Art 8[1]). **The Patient Rights' Charter adds information regarding the costs** (MOH, 2013, Chapter 1[8]). Guidelines on youth-friendly services indicate that legal requirements for engaging parents should be explained to youth (MOH, 2005, pg. 21). Finally, the HIV and AIDS **Prevention and Control Act defines consent as** “consent given without any force, fraud or threat and with full knowledge and understanding of the medical and social consequences of the **matter to which the consent relates**” (ROK, 2006, Art 2).

Policy language in Kenya is inconsistent as to the form that consent must take. HIV testing guidelines indicate that consent can be either written or oral—without identifying exceptions for children, but the HIV and AIDS Act indicates that if a child is tested, consent must be in writing **from the parent/guardian or “emancipated minor”** (ROK, 2006, Art 14[1][b]). In addition, the HIV self-testing guidelines indicate that verbal consent is sufficient (NAS COP, 2015, pg. 15). Policy language on the release of HIV-related information is also contradictory, with the Health Act indicating only written consent as acceptable (ROK, 2016, Art 11[2][a]) and the HIV and AIDS Act indicating that consent can be either written or oral (ROK, 2006, p. 22[1][d]).

## Findings

12. Policy language is inconsistent on whether written or oral consent is required for HIV testing of children and for sharing confidential HIV data.



## **Enforcement and Redress**

The Health Act fails to identify breaches of consent as an offence or to prescribe penalties such as are described for breaches of policy for other components of the Act, such as provision of emergency medical treatment, human organ transplant, blood transfusion, and participation in health information management systems (ROK, 2016, Art 7, 80, 85, 105). The HIV and AIDS Act identifies compulsory testing and testing without consent as offences (ROK, 2006, Sect 13, 14, 23). HIV service-specific guidelines do not identify enforcement and redress mechanisms for failures in the assent or consent processes. For example, while prohibiting coercive testing, HIV self-testing guidelines fail to identify specific mechanisms to prevent and address coercion, including clarification that coercive testing violates legal prohibitions against compulsory testing in the HIV and AIDS Prevention and Control Act (ROK, 2006, Art 14[4]; NASCOP, 2017, pg. 10, 15). Service guidelines for consent in the social welfare and education sectors are silent on enforcement and redress systems.

### **Findings**

13. The Health Act fails to identify breaches of consent as an offence.
14. HIV self-testing guidance fails to clarify that coercive HIV testing is a violation of compulsory testing prohibitions in the HIV and AIDS Prevention and Control Act.
15. Policy language identifying enforcement and redress for violations of consent are absent in HIV medical and social welfare guidelines.

## **Providing/Withholding Consent for Medical and Social Services**

The Kenya **Patients' Rights Charter identifies the right to informed consent to treatment** (MOH, 2013, Ch 1, Art 8), the Health Act identifies the requirement for patient consent for all health services (ROK, 2016, Art 9[1]), and the Children Act specifies that only one person needs to consent for a child (ROK, 2001, Art 24[6]). The HIV and AIDS Prevention and Control Act specifically identifies the requirement of consent for HIV testing, but not for any other service (ROK, 2006, Art 14), and it identifies training on informed consent as a required topic for healthcare providers (ROK, 2006, Art 6[3]).

While all stakeholders and service providers interviewed eloquently describe processes of engaging children and their caregivers in decisions regarding medical and social services, they also stated that these informed consent processes were mostly ad hoc due to a lack of specific, standardized guidelines and procedures.

Except for HIV testing, formal concepts of informed consent are mostly absent in HIV service-specific guidelines for both children and adults. The only specific reference to consent in HIV treatment guidelines was regarding the need for patient consent for providers to contact them by phone or during house visits (MOH, 2016, pg. 74). In addition, while processes like adherence and treatment readiness counseling are prime opportunities to ensure understanding of and consent for services, it is not clear that the counseling protocols specifically assess capacity to provide consent or require all components of consent—

Stakeholders identified a strong, albeit altruistic, intention to “facilitate” or “encourage” consent—representing an underlying personal and programmatic goal of universal participation in HIV services but perhaps jeopardizing long-term engagement and buy-in of clients and a related commitment to adherence.

especially the right to withdraw consent and withdraw from treatment at any time. For example, the script for gender-based violence screening does not seek consent or give the option to refuse (MOH, 2016, pg. 36). The Adolescents Package of Care was the only policy document identified that included the right to withdraw consent (MOH, 2014, pg. 13).

Policies on consent in the context of HIV self-testing are still evolving. The HIV and AIDS Act still assumes management of consent in the context of provision of HIV testing by a medical practitioner (ROK, 2006, Art 14). Furthermore, while the HIV self-testing manual emphasizes consent (NAS COP, 2017, pg. 15), there are no specific guidelines on how this will be achieved in a non-clinical setting.

Home-based care guidelines contain concepts like consulting and involving people living with HIV on matters concerning them (NACP, 2002), guidance for children caregivers identifies the importance **for the client's** well-being if clients are able to make choices about treatment (NCCS, 2011, pg. 150), and guidelines for charitable **children's** institutions give a general directive to obtain consent of the parent/guardian before involving children in activities (MGCS D, 2013, pg. 74).

The education sector health programming policy makes a general reference to allowing children to participate and express opinions in all matters that affect them (ROK, 2009c, pg. 25; ROK, 2009b, pg. 21). However, school health programming guidelines fail to mention or provide guidance on either child or caregiver consent for medical or social services (MOPH and MOE, 2009; ROK, 2009a).

Finally, there are examples of required interventions that by their compulsory nature violate the right to informed consent. These include required treatment for “venereal disease” until cured or noncommunicable (ROK, 2012b, Art 44, 46) and the requirement for girls to undergo “voluntary” medical screening for pregnancy once per term (ROK, 2009c, pg. 23; ROK, 2009b, pg. 17).

Annex B documents the service-specific policies that identify (or fail to identify) processes for obtaining consent.

## Findings

16. Requirements for consent are most clearly described for HIV testing. Other HIV-related services fail to identify consistent consent processes and requirements.
17. Social service guidelines fail to identify consistent consent processes and requirements.
18. Education sector health guidelines fail to identify consistent consent processes and requirements.
19. Required (compulsory) interventions violate informed consent—treatment for sexually transmitted infections until cured or non-communicable (ROK, 2012b, Art 44, 46) and the requirement for girls to undergo medical screening for pregnancy once per term (ROK, 2009c, pg. 23; ROK, 2009b, pg. 17).

## ***Providing/Withholding Consent for Management of Confidential Health Data***

The requirement to obtain informed consent for the release or sharing of confidential health data is a critical component of the right to confidentiality. Children and their caregivers must be

informed of their right to confidentiality and engaged in the planning of how, when, and to whom confidential health data should be disclosed (WHO, 2015, pg. 30). Protection of confidentiality has a direct relationship to increasing access to services and improving health outcomes as the risk of unconsented disclosure drives key, marginalized, and vulnerable populations, and adolescents living with HIV, away from services and discourages retention in care (WHO, 2013b, pg. 59).

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*The diagnosis of a client is not a community issue.*

(NACP, 2002, pg. 65)

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The following rights to privacy and confidentiality appear in the Kenya legal code:

- Right to privacy for information relating to family or private affairs (ROK, 2010, Art 31[c])
- Right to privacy and confidentiality for victims of crime (ROK, 2014c, Sect 8)
- Right to confidentiality regarding health status for persons deprived of liberty (ROK, 2014b, Part II[16])
- Requirement for patient consent for the release of confidential health information (ROK, 2016, Art 11[1],[2])
- Right to privacy and required written consent for the release of the result of an HIV test or any related assessments (ROK, 2006, Art 3[b][ii], Art 22[1][a],[c])
- Responsibility of individuals to seek permission before discussing or sharing an **individual's** HIV-status (NACP, 2002, pg. 65)
- Right to privacy and confidentiality for children subject to parental guidance (ROK, 2001, Sect 19)

Kenya documents identify the fear of breach of confidentiality of HIV data as a limitation to referral and networking (NACP, 2002, pg. 30). In addition, guidelines and strategies for youth-friendly services underscore the central ethical and legal value of privacy and confidentiality regarding health issues for children. Policy directs that this value of confidentiality must be upheld so diligently that there is not even the opportunity for children to feel or suspect that confidential data are being shared—including with parents (MOH, 2005, pg. 12, 15, 17, 21; NCCS, 2011, pg. 147-148; NCCS, 2015, pg. v).

In general, a good rule is that confidential data are only shared with the individual who has given consent for the medical or social intervention and that that individual retains the right to provide or withhold consent for further sharing of information regarding this intervention. For example, HIV testing guidelines direct that if a 15-year-old has consented for an HIV test, the decision of whether or not to share the results with parents/caregivers rests with that child (NAS COP, 2015, pg. 27). The 2006 HIV and AIDS Prevention and Control Act aligns **“emancipated minor’s”** consent to test, **release of information only to the “tested person,”** and the requirement to obtain consent of that individual to disclose HIV-related information (ROK, 2006, Sect 14[1][b], 18[a][b], 22[1][c]). However, the HIV and AIDS Prevention and Control Act directs that post-test counseling be provided to the **person undergoing an HIV test and “any other person likely to be affected by the results of such test”** without mentioning the need to get the consent of the tested person **to engage “other persons”** (ROK, 2006, Art 17[1]).

The practice of aligning consent provided by a child for interventions with consent from that child for the sharing of confidential data is not uniformly described in other policy documents. The following policy examples fail to provide guidance or recognize that a child can consent for interventions as an emancipated minor or someone over the age of 15 years.

- “Parents should disclose the status of their children to facilitate treatment and **adherence**” (NAS COP, 2015, pg. 13).
- “**Every** health care provider shall inform a user or, where the user of the information is a **minor or incapacitated, inform the guardian**” (ROK, 2016, Art 8[1]).
- “**HIV test results for children up to 14 years will be given to the parents/guardians whose consent is needed for testing them**” (NAS COP, 2015, pg. 27).

Programmatically, confidentiality is identified as a required topic in the training of healthcare providers (ROK, 2006, Art 6[3]) and caregivers of children in institutionalized settings (MGCSD, 2013, pg. 31–32). Confidentiality is emphasized throughout home-based care guidelines for both patients and family/caregivers, and trainings for home-based care emphasize the potential for and include issues related to conflicts in confidentiality requirements (NACP, 2002, pg. 25). Childcare guidelines identify the optimal practice of written consent (even for family members) to identify who has access to medical records and permission to divulge information concerning the family or children (NCCS, 2011, pg. 147–148, 150).

**The National School Health Policy identifies the child's right to privacy and confidentiality** regarding their health and restricts sharing of health status and medical conditions with other children without the consent of the child or legal guardian; however, it also states that medical **information may be accessed by blanket categories of “health personnel, parents, and teachers”** for broad, vague reasons such as “**providing medical advice**” and “**preventing spread of infectious disease**” **without** requiring consent for that access (ROK, 2009c, pg. 16, 17). School health implementation guidelines fail to address confidentiality or provide guidance on how consent for sharing confidential health data is managed (MOPH and MOE, 2009; ROK, 2009a). Given these weak standards of consent for sharing of confidential HIV information in the education sector, it is not surprising that stakeholders shared examples of breaches of confidentiality of students' HIV status in school settings.

There is conflicting policy guidance regarding the assumption that people living with HIV will share their confidential HIV data. Testing guidelines recognize that clients may not be in a supportive environment and may experience stigmatization and discrimination, and that the sharing of their HIV status “**should not be treated as an event that must happen**” (NAS COP, 2015, pg. 26–27). However, other policy language assumes and requires that people living with HIV will share their confidential HIV data. HIV testing policy emphasizes that HIV-positive youth should be encouraged to share their status with parents/caregivers, and that in the event of challenges, the provider should support disclosure (NAS COP, 2015, pg. 12, 27). Willingness to share **one's HIV status is a** criterion listed in the ART readiness assessment with the accompanying directive that if the response to this criterion is “**No,**” there should be a strategy to address the issue as quickly as possible, with the potential for deferment of ART until the criterion is met (MOH, 2016, pg. 71). Home-based care guidelines indicated that the HIV-status of the individual *will* be known to the caregivers, the **individual's** spouse, and, if the individual is not married, the parents—**instructing the counselor to “prepare the PLWHA** [person living with HIV] well enough to be able to communicate the diagnosis to the relevant people with **ease.**” It is further indicated that this shared confidentiality will alleviate fear and

suspicion among the immediate family members (NACP, 2002, pg. 65)—contradicting the philosophy of the best interest of the child by identifying the emotional comfort of the family on par with or above the best interest of the person living with HIV.

## Findings

20. The HIV and AIDS Prevention and Control Act fails to require consent from the tested individual for “other persons” to be involved in post-test counseling.
21. Multiple policy documents do not recognize the possibility of “emancipated minor” consent for testing and the aligned right of that child to provide/withhold consent for the sharing of confidential HIV data.
22. The National School Health Policy and practice gives permission to share confidential HIV data with broad categories of people without the consent of the child or caregiver.
23. The requirement of obtaining consent before sharing confidential HIV data is not addressed in school health guidelines.
24. Multiple programmatic guidelines (e.g., HIV testing guidelines, ART readiness protocols, and home-based care guidelines) fail to recognize the right of HIV-positive people to withhold consent for the sharing of confidential HIV data.
25. Best practices for childcare include a strong emphasis on confidentiality and having clients give permission to divulge confidential information. However, the definition of client is not clear and seems to include both children and parents/guardians, and while there is recognition of the capacity to make informed choices, there is no guidance on protocols for implementation (NCCS, 2011, pg. 147–148).

## Shared Confidentiality

The sharing of confidential HIV data among direct provider teams is known as shared confidentiality. Shared confidentiality within a service setting and among direct provider teams facilitates provision of quality services. In addition, it is clear that holistic clinic- and community-based services and support are required for positive health outcomes. However, the role of providers is to identify and refer clients to resources rather than share confidential HIV data outside of the direct provider team. Only with specific consent of the child or caregiver can providers directly engage or share information with external individuals or services (WHO and UNICEF, 2010, pg. 10; WHO, 2014, pg. 5, 6, 8; WHO, 2015, pg. 63). Providers in community, education, and detention settings fall under the same requirements to respect rights to privacy and confidentiality as do those in healthcare settings, which limits the sharing of confidential **health data outside of the direct “care” team** (UN, 1985, Sect V.87.e; IASSW and IFSW, 2000, pg. 1; WHO, 2003, pg. 13; RELAF and UNICEF, 2011, pg. 24; WHO, 2013b, pg. 60).

**The purpose and scope of “shared confidentiality,”** even within a service setting, should be discussed with the child and their caregiver to obtain agreement as to (1) the benefits of the provider team knowing this information, (2) the confidentiality protections and procedures that prohibit sharing beyond this team, and (3) strategies to address any risks that might be present (e.g., friends/family working in the clinic) (WHO, 2015, pg. 29).

Kenya policy language provides limited and conflicting guidance on shared confidentiality—sometimes within the same policy statement. For example, HIV testing guidelines state, “**Confidentiality is not secrecy. Client’s names will be used in order to facilitate**

referral to other services and test results may be shared with other health care workers **providing services to the client; referred to as shared confidentiality**" (NAS COP, 2015, pg. 19). Similarly, the guidelines state that **"a health care provider may disclose patient HIV results to another provider for purposes of further care/management"** (NAS COP, 2015, pg. 27). Neither of these statements places limits on providers, defines services, or provides a requirement for consent for the sharing of this information. However, other statements in the same document identify the **scope of information sharing as being among "health care workers who are directly involved in the management of the client"** (NAS COP, 2015, pg. 28), and it is only a disclosure scenario graphic that seems to indicate the requirement of client consent for sharing confidential information with a third party healthcare worker (NAS COP, 2015, pg. 29). The sum of these statements is inconsistent direction on how and when consent is needed for the sharing of confidential HIV data and complete omission of the engagement of the client in decisions being made about sharing their confidential HIV data within a direct provider team.

Guidelines in the social and education sectors, in general, provide supportive language regarding confidentiality but fail to provide clear guidance of when and how confidential HIV data are shared among a provider team and how to engage the child in this decision. Guidelines for children caregivers describe confidentiality as a legal and ethical obligation. However, they are also unclear about who makes decisions to share information with whom. While there is an overarching directive that caregivers share **information on a "need to know" basis**, there is no description of what that means. Use of the word **"client" is unclear**, whether it is a child or their caregiver, **and terms like "unauthorised" and "authorised" persons do little to distinguish** between core providers and other individuals (NCCS, 2011, pg. 147–148). **Guidelines for charitable children's institutions indicate that the institution "shall avail a child's information to any person" and seem to define** core providers as those working **"in the best interest of the child e.g. child welfare, exit purposes and other relevant positive intentions"** (MGCSD, 2013, pg. 31–32). In addition, the Education Sector Policy on HIV and AIDS identifies protections for confidentiality but also the directive to **"establish mechanisms for confidentially identifying learners living with HIV including those with special needs for appropriate support at all levels"** without discussion of consent for collecting these confidential HIV data (ROK, 2013, pg. 13).

In the medical sector, referrals for services outside of the core care team use triplicate referral forms, which by their nature disclose confidential HIV information (NAS COP, 2015, pg. 20, Annex 1). Stakeholders interviewed described these forms as shared with providers either by client-initiated or direct provider-to-provider distribution, with the former approach giving the client control over the sharing of their confidential HIV data. Stakeholders also suggested that adding a simple client consent statement and signature to the form would provide a reminder to providers to obtain consent from the client before sharing their information. Consistent guidance regarding the need to obtain consent for the sharing of confidential HIV data beyond core care teams will be critical for any integrated service structure, such as:

- Coordination of care and treatment among partners and families (MOH, 2016, pg. 17)
- Family-based case management
- Electronic health information systems (ROK, 2016, Part XV)
- Single registries for social welfare programs across target groups and program areas (ROK, 2011, pg. 27)

## Findings

26. Guidance on engaging a child and/or caregiver in understanding the shared confidentiality of their HIV data is absent in all sectors.
27. Consistent definitions and practices for requiring consent for the sharing of confidential HIV data between direct provider teams and external providers are absent for all HIV health and social services.
28. Education sector policy directs collection of confidential HIV data without mechanisms for obtaining consent for the collection of these data.

## Authorization and Capacity to Provide Consent

### *Capacity to Act in the Best Interests of the Child*

Proxies (whether provider, biological parent, guardian, or caregiver) who support children in assent/dissent and make decisions to provide/withhold consent to HIV medical or social interventions or the sharing of confidential HIV data must have the capacity to act in the best interests of the child. When observing the interactions of a proxy and child, the following characteristics should be present:

- The proxy identifies and protects the child from emotional, physical, sexual, or religious abuse.
- The proxy engages in respectful, two-way communication with the child.
- The proxy fosters self-resiliency in the child.
- **The proxy is nonjudgmental of the child's HIV status and risk behaviors** (HP+, forthcoming).

Kenya social welfare and HIV policies identify factors that may present barriers to these responsibilities that include health, ability to understand, depression, alcohol and other drug use, distance, economic stability, level of affection, support systems for the caregiver (MOH, 2016, pg. 73), and any environment of abuse, neglect, and exploitation (ROK, 2014c, Sect 18; MLSS&S, 2015, pg. 21). Correspondingly, policy documents identify the need to assess and build **caregiver capacity to support a child's right to engage in decisions about their life** (MLSS&S, 2015; MOH, 2015, pg. 66). These policies focus on the capacity of the parent, guardian, or caregiver, but there is no policy language about assessing and developing the capacity of providers who find themselves in the role of supporting a child in making decisions about their services or management of their confidential data.

Kenya HIV guidelines also identify the importance of building a therapeutic relationship between provider and patient that is independent of caregivers (MOH, 2015, pg. 61), as well as the importance of adolescent identification of supportive adults and friends for linkage to care and treatment (MOH, 2016, pg. 17) and adherence (MOH, 2016, pg. 79).

## Findings

29. Policy guidance on assessing and developing the capacity of providers to engage children in consent processes is absent in all sectors.



## Children

The standard for consent in Kenya is “legal capacity,” which is age 18 years (ROK, 2012a, Sect 2; ROK, 2016, Art 9[3]). For HIV testing, current language identifies the requirement for child assent and parental/guardian consent *up to* the age of 14 years and child consent at age 15 (NAS COP, 2015, pg. 18). This current policy language leaves out guidance on authority to consent for children *in* their fourteenth year, but common implementation of the law assumes the need for parent/guardian consent *through* the fourteenth year. There is also no reference to the age at which children can purchase HIV self-test kits (NAS COP, 2017). There is a vague **reference in the ART guidelines that “all PLHIV [people living with HIV] qualify for ART irrespective of ... age”** (MOH, 2016, pg. 19). However, this guidance does not address the subject of consenting for treatment. Additionally, child survivors of sexual violence may be tested without the consent of parents/guardians, provided that they are given age-appropriate counseling (NAS COP, 2015, pg. 16). The challenge with this current policy structure is that without clear guidance that aligns age of consent for testing with other HIV services, children under the age of 18 can consent to HIV testing but technically need to have caregiver consent for ART, social welfare services, or decisions related to confidential HIV data.

### Findings

30. Policy for age at which children can use HIV self-testing technologies is absent.
31. Current policy language does not provide guidance on authority to consent for HIV testing for children in their fourteenth year.
32. Policy language on authorizing consent for testing does not align with policy language authorizing consent for other HIV services.

## Emancipated Minors

There is no formal and consistent definition of emancipated minor in the legal code. The HIV Testing Services Guidelines defines an emancipated minor as “a person, who is not legally an adult but who, because he or she is married, is the mother/father of a child, or otherwise no longer dependent on the parents. S/he may not require parental permission for **medical or surgical care**” (NAS COP, 2015, pg. x). The HIV and AIDS Prevention and Control Act, does not **specify the classification of “emancipated minor” but allows for a “child that is pregnant, married, a parent, or is engaged in behaviour which puts him or her at risk of contracting HIV” as having the authority to consent to an HIV test** (ROK, 2006, Art 14[1][b]). These two descriptions fail to align on the critical component of behavioral risk.

The definition of emancipated minor is not included in the Health Act (ROK, 2016), Children Act (ROK, 2001), or National Children Policy (NCCS, 2010), giving limited support to the concept and implementation of emancipated **minor consent. Also, the reference to “medical and surgical care” for which parental permission “may not” be required is vague and not within the scope of HIV testing guidelines.** Finally, there is no corresponding reference to the ability of emancipated minors to consent for any other HIV service other than HIV testing (ROK, 2009a; ROK, 2011; MOH, 2012, 2014, and 2016; NAS COP and MOH, 2017).



## Findings

33. Definitions of emancipated minors are not consistent or integrated into relevant documents.
34. Policy language stating that emancipated minors may not require permission for medical or surgical care is unclear and beyond the scope of HIV testing guidelines.

## Parents

Engagement of a parent is not always possible or in the best interests of the child. Parents may be absent (e.g., migrant workers), incapacitated (e.g., ill health), or judgmental and unsupportive of the services required for children from key, marginalized, and vulnerable populations (WHO, 2013b, pg. 19; UNICEF, 2015, pg. 9, 10). In cases where children seek HIV prevention, testing, care, or treatment without parental consent, it stands that they may do so because of lack of parental involvement or fear of revealing stigmatized behaviors. (Chenneville et al., 2010). Current social welfare and HIV policy language identifies the need to assess and build capacity of parents and caregivers to act in the best interests of the child (MLSS&S, 2015; MOH, 2015, pg. 66) but does not provide guidance on how to do this assessment or what to do if a parent is **unable to be a supportive presence in a child's life**.

## Finding

35. Policy language is absent on how to assess and develop the capacity of parents to act in the best interests of a child and how to respond if a parent is unable to be a supportive presence in a child's life.

## Caregiver versus Guardian

In general, when referring to a non-**parent in a child's life**, **health sector documents tend to use** the term guardian, identifying a legal relationship with the child (ROK, 2006, Art 2; NCCS, 2011, pg. 7), and social welfare sector documents use the term caregiver, which includes broader supportive roles in care and well-being, including biological parents, children in the family, relatives and house help (*ayahs*), teachers, health workers, law enforcement officers, children officers, and workers in children's homes and statutory institutions, among others (NCCS, 2011, pg. 7, 10; MLSS&S, 2015, pg. v).

As identified in Annex B, the discrepancy between caregiver and guardian creates contradictions in who has **the authority to support a child's consent**, depending on the service and sector. It also can create confusion as to who, among legal guardians and perhaps multiple caregivers, actually has the authority to provide consent. Given the complex relationships between children and parents, guardians, and caregivers, stakeholders interviewed recommended moving to consistent use of the term and concept of caregiver, noting that further mechanisms would need to be put in place to identify which caregiver had authorization to provide consent.

## Finding

36. Policy language inconsistently uses the terms "guardian" and "caregiver" in different sectors.

## Providers

In circumstances where no one is available or willing to provide consent for a child, and life-saving treatment is available, a health or social service provider should provide consent and initiate testing, interventions, or the sharing of confidential health data if it is in the best interests of the child (WHO and UNICEF, 2010, pg. 3, 7, 8).

Policy language in Kenya only allows for healthcare providers to consent for HIV testing of individuals with disabilities that would restrict their ability to provide consent and where there is no other person present or willing to give consent (ROK, 2006, p. 14[1][c]; MOH, 2015, pg. 83, 84).

As a general principle, when life-saving treatment is available, and all efforts to obtain parental consent have failed, the provider has an ethical responsibility to act in the best interests of the child (WHO and UNICEF, 2010, pg. 3).

## Finding

37. The Health Act does not authorize health service providers to provide consent for children who may not have a present or supportive parent or caregiver.

## Summary

The policy and guideline framework related to **consent for children's access to HIV**-related social and medical services and management of confidential HIV data is a patchwork of conflicting, inadequate, and often absent policy. This fragmented policy environment contributes to the programmatic experience described by providers, policymakers, and adolescent representatives in which consent practices for children are ad hoc and inconsistent. This environment contributes to risk for providers in an increasingly litigious culture, as well as children for whom consent may not be sought or obtained.

Findings of the policy assessment can be divided into two groups. In the first group is the enforcement and enactment of existing rights to health, protection from harmful cultural practices, ensuring the best interest of the child, and maturity-aligned participation. The second group consists of the need for service-specific policy guidance that is consistent across health, social welfare, and education sectors for clear and consistent assent and consent guidelines related to medical and social HIV services and sharing of confidential HIV data.

## Annex A: Summary of Findings

1. While the right to reproductive healthcare is well established, access to and consent for pre-exposure prophylaxis for HIV is not clearly defined and is indirectly restricted for those under the age of 15—with or without parental/caregiver consent.
2. Children are broadly protected from activities and beliefs that negatively impact their health; **however, the religious and cultural beliefs of providers are still significant barriers to youth's** access to reproductive health services.
3. The Children Act does not reflect the standard of ensuring that the best interests of the child are paramount, as reflected in the Constitution (may be resolved in the new 2018 Children Act).
4. The Guidelines for Alternative Care are inconsistent in their prioritization of the best interests of the child.
5. Guidelines for the education sector do not reflect the standard of ensuring that the best interests of the child are paramount, as reflected in the Constitution.
6. HIV policies are entirely silent on the paramountcy of the best interests of the child.
7. Existing indicators of capacity to consent are biological, social, and behavioral markers, rather than cognitive and emotional maturity measurements.
8. A maturity qualification to authorize an individual to provide consent is absent in overarching and HIV-specific health policy language.
9. Guidance on how to assess maturity is absent in existing language supporting maturity-aligned engagement.
10. Policy language on child assent is largely absent in the health sector.
11. There is no specific policy guidance on the requirements and components of assent or the process for managing dissent.
12. Policy language is inconsistent on whether written or oral consent is required for HIV testing of children and for sharing confidential HIV data.
13. The Health Act fails to identify breaches of consent as an offence.
14. HIV self-testing guidance fails to clarify that coercive HIV testing is a violation of compulsory testing prohibitions in the HIV and AIDS Prevention and Control Act.
15. Policy language identifying enforcement and redress for violations of consent are absent in HIV medical and social welfare guidelines.
16. Requirements for consent are most clearly described for HIV testing. Other HIV-related services fail to identify consistent consent processes and requirements.
17. Social service guidelines fail to identify consistent consent processes and requirements.

18. Education sector health guidelines fail to identify consistent consent processes and requirements.
19. Required (compulsory) interventions violate informed consent—treatment for sexually transmitted infections until cured or non-communicable (ROK, 2012b, Art 44, 46) and the requirement for girls to undergo medical screening for pregnancy once per term (ROK, 2009c, pg. 23; ROK, 2009b, pg. 17).
20. The HIV and AIDS Prevention and Control Act fails to require consent from the tested **individual for “other persons” to be involved in post**-test counseling.
21. **Multiple policy documents do not recognize the possibility of “emancipated minor” consent** for testing and the aligned right of that child to provide/withhold consent for the sharing of confidential HIV data.
22. The National School Health Policy and practice gives permission to share confidential HIV data with broad categories of people without the consent of the child or caregiver.
23. The requirement of obtaining consent before sharing confidential HIV data is not addressed in school health guidelines.
24. Multiple programmatic guidelines (e.g., HIV testing guidelines, ART readiness protocols, and home-based care guidelines) fail to recognize the right of HIV-positive people to withhold consent for the sharing of confidential HIV data.
25. Best practices for childcare include a strong emphasis on confidentiality and having clients give permission to divulge confidential information. However, the definition of client is not clear and seems to include both children and parents/guardians, and while there is recognition of the capacity to make informed choices, there is no guidance on protocols for implementation (NCCS, 2011, pg. 147–148).
26. Guidance on engaging a child and/or caregiver in understanding the shared confidentiality of their HIV data is absent in all sectors.
27. Consistent definitions and practices for requiring consent for the sharing of confidential HIV data between direct provider teams and external providers are absent for all HIV health and social services.
28. Education sector policy directs collection of confidential HIV data without mechanisms for obtaining consent for the collection of these data.
29. Policy guidance on assessing and developing the capacity of providers to engage children in consent processes is absent in all sectors.
30. Policy for age at which children can use HIV self-testing technologies is absent.
31. Current policy language does not provide guidance on authority to consent for HIV testing for children in their fourteenth year.
32. Policy language on authorizing consent for testing does not align with policy language authorizing consent for other HIV services.

33. Definitions of emancipated minors are not consistent or integrated into relevant documents.
34. Policy language stating that emancipated minors may not require permission for medical or surgical care is unclear and beyond the scope of HIV testing guidelines.
35. Policy language is absent on how to assess and develop the capacity of parents to act in the best interests of a child and how to respond if a parent is unable to be a supportive presence **in a child's life**.
36. **Policy language inconsistently uses the terms "guardian" and "caregiver" in different sectors.**
37. The Health Act does not authorize health service providers to provide consent for children who may not have a present or supportive parent or caregiver.

## Annex B: Children's Consent Summary

Service	Consent Process (not specified—assumption)	Authorized to Provide Consent (not specified—assumption)	Reference
All health services	Consent	<ul style="list-style-type: none"> <li>• Patient or their appointee</li> <li>• Next of kin</li> <li>• Requires legal capacity</li> </ul>	ROK, 2016, Art 9
Provider-initiated HIV testing and counseling	Consent	(Service- and context-specific guidelines)	MOH, 2016, pg. 15
HIV testing < 18 months	(Provider-initiated HIV testing and counseling)	(Parent or appointee)	MOH, 2016, pg. 8
HIV testing 18 months–9 years	Assent	Parent (or appointee)	MOH, 2016, pg. 8
HIV testing	Consent	<ul style="list-style-type: none"> <li>• 7–13 years assent with consent of parent/guardian/caregiver</li> <li>• 15+ years</li> <li>• Emancipated minors</li> </ul>	MOH, 2016, pg. 8; NASCOP, 2015, pg. 18
HIV self-testing	Not specified	Not specified	MOH, 2016, pg. 7, 9; NASCOP, 2017
Pre-exposure prophylaxis	Adherence readiness counseling	15+ years	MOH, 2016, pg. 130
Post-exposure prophylaxis	Consent	Patient; no guidance on < 18 years	MOH, 2016, pg. 127
Infant ARV prophylaxis/DNA PCR testing/ART initiation	(Provider-initiated HIV testing and counseling)	(Parent or appointee)	MOH, 2016, pg. 8
HIV education and adherence counseling	Collaborative	Patient or caregiver	MOH, 2016, pg. 65
Second/third-line ART	(Treatment readiness assessment)	(Patient or caregiver)	MOH, 2016, pg. 64, 67, 83, 87, 88
Enhanced adherence counseling	(Collaborative)	(Patient or caregiver)	MOH, 2016, pg. 81–83
Medication and appointment adherence support: <ul style="list-style-type: none"> <li>• Case management</li> <li>• Disclosure</li> <li>• Home visits</li> <li>• Treatment supporters</li> <li>• Directly observed therapy</li> <li>• Support groups</li> </ul>	Enhanced adherence counseling	(Patient or caregiver)	MOH, 2016, pg. 74, 81–83, 151

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Service	Consent Process (not specified—assumption)	Authorized to Provide Consent (not specified—assumption)	Reference
Referrals	Collaborative discussion	(Patient or caregiver)	Stakeholder interviews; MOH, 2016, pg. 17
Sharing confidential data within provider teams	(Assumed)	(Not required)	MGCSD, 2013; ROK, 2013; NASCOP, 2015
Sharing confidential data with service providers beyond care team	<ul style="list-style-type: none"> <li>• Collaborative decisions</li> <li>• Patient personally transfers data</li> <li>• Provider directly transfers data</li> </ul>	(Patient or caregiver)	Stakeholder interviews; no formal guidance
Sharing child's confidential data in school settings	Consent	Consent from child or guardian for sharing with other children	ROK, 2009c, pg. 16, 17
	No consent	No consent required for sharing with health personnel, parents, and teachers	ROK, 2009c, pg. 16, 17
	Guided by best interest of child	Not specified	ROK, 2013, pg. 6
Screening for gender-based violence	Not specified	<ul style="list-style-type: none"> <li>• Females 15+ years</li> <li>• Emancipated minors</li> <li>• No guidance on &lt; 15 years</li> </ul>	MOH, 2016, pg. 36
Medical care after rape	Informed written consent	Survivor or guardian	MOH, 2014, pg. 49
Home-based care	Consultation but assumed disclosure	People living with HIV	NACP, 2002
School-based health services	Not specified	Not specified	ROK, 2009c, pg. 25; MOPH and MOE, 2009, pg. 21
Activities for institutionalized children—unclear if applies to HIV/health	Voluntary participation of child	Parent/guardian	MGCSD, 2013, pg. 73, 74
Medical interventions for institutionalized children	Consent	<ul style="list-style-type: none"> <li>• Next of kin or legal custodian</li> <li>• Authority of staff</li> </ul>	MGCSD, 2013, pg. 53, 54
Care for children	Agreement and choice between alternatives	Client (parent or child?)	NCCS, 2011, pg. 150
Tracing and reintegration services	Signed consent form	Child, family, and respective organization	ROK, 2014a, pg. 35
Kinship care	Consent	Family	ROK, 2014a, pg. 47
Kafaalah	Consent	Relative/involvement of institution management	ROK, 2014a, pg. 51

## Annex C: Consultation Attendees

Name	Organization	Title
Kevin Kipkan	COGRIL (LEA TOTO PROGRAM)	Peer Educator
Florence Nyandwaro	COGRIL (LEA TOTO PROGRAM)	Psychologist
Rodah Jemeli	COGRIL (LEA TOTO PROGRAM)	OVC Program Coordinator/Social Worker
Lucy Alivitsa	COGRIL (LEA TOTO PROGRAM)	Peer Educator
Christopher Muthoka	AFYA JIJINI	Technical Officer
Shelvin Mairura	HP+ Kenya	Program Officer
Betty Odera	AFYA JIJINI	CEA
Susan Ouma	Department of Children Services	DC5
Rose Mokaya	USAID/KEA	PMS/OVC
Florence Kabuga	CHO	SNO
Leah Rutto	NCCG-CHO	CNCAH
Lillyan M. Mutua	NCCG-CHO	CHPC
Valerie Ndege	PM-NILINDE	PM
Ashley Gibbs	HP+	Sr. Associate
Kip Beardsley	HP+	Senior Technical Advisor



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For more information, contact:

Health Policy Plus  
Palladium  
1331 Pennsylvania Ave NW, Suite 600  
Washington, DC 20004  
Tel: (202) 775-9680  
Fax: (202) 775-9694  
Email: [policyinfo@thepalladiumgroup.com](mailto:policyinfo@thepalladiumgroup.com)  
[www.healthpolicyplus.com](http://www.healthpolicyplus.com)

